Hamilton-Wentworth District Health Council
Conseil régional de santé de Hamilton-Wentworth

2000/2001 DIRECTIONS FOR LONG TERM CARE PLANNING

February 2000

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SUMMARY OF PROPOSED DIRECTIONS FOR LONG TERM CARE PLANNING

1. *HWDHC to develop a supportive housing plan in partnership with community stakeholders, which would include a review of the appropriateness of the current supportive housing policy and funding levels. The planning process should explore the potential development of residential settings which can provide multiple levels of care.*

   The consultation process identified the following principles for the development of a supportive housing plan:
   - *Policy needs to be inclusive and flexible to address a variety of models.*
   - *The process should include the quantification of need for units and the required levels of service within those units.*

2. *HWDHC to develop a respite plan in partnership with community stakeholders.*

   The consultation process identified the following principles for the development of a respite plan:

   - *Funding needs to be "client centred" and "caregiver centred"*
   - *All LTC Populations/age groups need access to respite*
   - *There need to be multiple options for service delivery – self-managed, regular planned, emergency and crisis prevention*
   - *There needs to be flexibility between options and within options*
   - *Respite needs to be accessible*
   - *The system needs to be accountable*
   - *The system needs to include end-of-life respite care*

3. *HWDHC staff to review the Regional Transportation Master Plan, the activities of the Regional Transportation Committee, and the recommendations of the Regional Progress Team to summarize what initiatives and recommendations currently exist in the area of transportation initiatives for LTC populations.*

4. *HWDHC to invite the Volunteer Centre to take a lead role in bringing together LTC community agencies, consumers, volunteers, the Ministries of MCSS, MOHLTC, Citizenship and Recreation, and the Regional Municipality to develop a community marketing strategy to enhance volunteer recruitment.*

5. *HWDHC undertake a community mapping of LTC services.*

6. *HWDHC staff develop and update a listing of planning and coordinating groups in Hamilton.*

7. *The Ministry of Health and Long-Term Care support the development of a Minimum Data Set and the infrastructure required to support the local development of a system of information management.*

8. *The HWDHC work with the community on identifying the elements of a welcoming environment*

1.0 BACKGROUND AND METHODOLOGY

1.1 WHAT IS LONG-TERM CARE?

Long-term care (LTC) refers to the broad range of personal care, support and clinical services provided to individuals who have limitations that prevent them from participating independently in everyday activities. The goal of long-term care is to ensure the residents of Hamilton-Wentworth have simplified, timely, equitable access to a full range of co-ordinated long-term care services that optimize health, well-being and independence, and enhance quality of life.

Major client groups for long-term care services include elderly persons in need of long-term care and support services, individuals over 16 years of age with physical disabilities who need help to work, go to school or take part in day-to-day activities, children who require health services at home or at school, and caregivers. Services included in this sector are:

- Adult Day Services
- Meal Services (Meals on Wheels/Diners Club/Wheels to Meals/Congregate Dining)
- Transportation
- Friendly Visiting
- Security Checks/Reassurance Service
- Caregiver Support/Respite
- Home Help/Home Maintenance and Repair
- Client Intervention and Assistance Services
- Supportive Housing & Attendant Care Outreach Services
- Professional Services & Homemaking
- Children's Services
- Life Skills Services
- Social Recreational Service
- Special Services for the Blind or Hearing Impaired
- Palliative Care Initiatives

Most long term-care services are funded by the Ministry of Health and Long-Term Care (MOHLTC). Other major funders include the Ministry of Community and Social Services which funds most children's services, the United Way, the Regional Municipality, and faith denominations. Many agencies also do extensive fundraising.

1.2 THE ANNUAL DISTRICT SERVICE PLAN

Each District Health Council is responsible for the development of an Annual District Service Plan (ADSP[1]), as well as a strategic Multi-Year District Service Plan (MYP) for community long-term care services. The HWDHC finalized its Multi-Year Plan in January 1997.

1 No ADSP Plan was developed for 1999/2000, as per MOHLTC approved 99/2000 HWDHC Operating Plan

Each district is allocated a long-term care envelope to fund long-term care community services. This system was developed to allow for greater flexibility for each community to respond to specific issues or needs while ensuring equity of access across the province. District Health Councils have been mandated to plan for services within the funding envelope and make recommendations to the Minister for service improvements and changes that should occur each year. The Hamilton-Wentworth District Health Council (HWDHC) has been advised that there will be no new funding for community-based long-term care services for an indefinite period of time.

The range of issues an ADSP can address include:

- the service improvements and changes that should occur each year in the community long-term care sector
- recommendations for service expansions and reallocation of service resources under the community services funding envelope for long-term care services
- recommendations for policy changes, and
- a workplan for how the community could respond to service gaps and delivery challenges.

An ADSP also includes demographic information, highlighting what we know about the potential need for service.

1.3 PLANNING APPROACH

The approach for the 2000/2001 Annual District Service Plan is to identify a set of directions based on previous planning reports and consultations. It is anticipated these directions will assist the HWDHC, the MOHLTC, and the community focus on relevant issues and planning activities that will make a difference in the lives of long-term care consumers, providers and caregivers.

1.4 THE PLANNING PROCESS

Staff developed a draft list of issues/pressure points from four sources:

- A review of issues identified by consumers in written reports over the past 10 years. (Sept. 99)
- A review of service trends and service delivery challenges identified in the 1998/99 Agency Operating Plans (Nov. 99)
- The results of an agency survey updating recommendations from HWDHC Long-Term Care Annual District Service Plans and the Multi-Year Plan (Nov. 99)
- The results of an agency survey identifying current service challenges and issues. (Nov. 99)

The issues for review were identified using the following criteria:

- issues identified numerous times
- issues which were identified by both consumers and providers
- issues that were conducive to local action

The draft list was reviewed by the Long-Term Care Advice Group[2] for validation, and assistance with presentation to a community workshop.

Two overarching themes across all issues emerged:

- an increase in the complexity of client care and support, with significant implications for volunteer capacity, housing and transportation systems; and
- a perceived lack of funding in the community based long term care sector.

The next step in the process involved two community workshops; one on November 25th to determine the relative ranking of the identified directions and a second session on December 7th to identify strategies to move those issues ahead.

Participants reflected a diversity of consumer and provider perspectives from across the Region and a wide range of knowledge across the following: on type of service – i.e. food, housing; type of organization - i.e. small, large, multi-service, single-service; and population groups – i.e. seniors, individuals with a disability, and caregivers of children using LTC services, and other caregivers. Participants also included individuals from sectors normally associated with long-term care services, including hospitals, children's services, and mental health services. The process also included key informant interviews, and a review of issues in other healthcare sectors.

The following directions, identified from the information review and revised at the first consultation, provided the basis for further discussion at a subsequent session.

- Interim strategies to support people in the community pending additional long-term care facility beds
- Supported housing for seniors/Supportive housing/Attendant care outreach
- Respite, including Adult Day Services and Support for Caregivers
- Transportation
- Human Resources, both paid and volunteer
- Integrated services to serve clients better through:
  - Enhanced collaboration
  - Sharing of best practices
  - Accountability to each other, including clients
  - Coordination of children's services
- How We Provide Service - Models of Service Delivery
  - Welcoming environments
  - Client-focused
  - Accessibility

There was a recognition that each of these issues applies to each of the traditional long-term care populations (seniors, adults with physical disabilities, children requiring long-term care services, caregivers) as well as individuals with dementia. There are other particular populations, such as

2 The Long-Term Care Advice Group is a small committee that offers process advice to the DHC in the area of LTC

those with visual or hearing impairments, who will need to be considered in future planning work.

2.0 ISSUES AND STRATEGIES

2.1 LTCF BED SHORTAGES – AN INTERIM STRATEGY

2.1a Issue Identification

The data and community experience reflect the lack of LTCF beds to meet needs in Hamilton-Wentworth, which has among the lowest per-capita LTCF bed rates in Ontario.

The Ministry of Health and Long-Term Care currently funds 2505 permanent LTCF beds and 102 interim beds in Hamilton-Wentworth. In April 1998, the Ministry announced they would be funding an additional 1308 LTCF beds in Hamilton-Wentworth. Contracts for 550 beds were announced in November 1998; an additional 150 beds were announced for the St. Peter's Hospital site, but these beds are not yet operational. An RFP for 202 additional beds is currently in place, and those groups awarded beds should be announced shortly.

The waiting list data support the need for more beds.

Waiting list for Long-Term Care Facilities, January 14, 2000

Category	Currently in:				Totals:
	Community	LTCF	Chronic/ Acute Care	Other[1]	
1 – Urgent	7	1	0	2	10
2 – Special needs	20	9	6	4	39
3 & 4 All others	536	420	152	118	1226
Total	563	430	158	124	1275

Source: Placement Coordination Services, CCAC, January 2000.
[1]This category includes other locations, as well as those from other Placement Coordination Services. This data all reflects individuals from other Placement Coordination Services.

The Special Needs category encompasses those individuals who are of a particular cultural faith, or in a spousal situation, or in a situation where beds and facilities are closing. They also include persons in current interim LTCF beds.

Comparison of Current LTCF Beds with HSRC Targets for Selected Districts

Selected District	Number of LTCF beds	Population Projections for Elderly Populations, 2003, HSRC	2003 HSRC Target for Additional LTCF beds	1996 Beds per 2003 pop'n	HSRC Bench mark	Difference between current and benchmark	MOHLTC 2006 Total New Allocation
Brant	744	9172	168	81.12	99.10	-17.98	122
Durham	2044	26520	528	77.07	99.10	-22.-3	847
Essex	1991	25761	511	77.29	99.10	-21.81	577
Haldimand-Norfolk	806	7872	0	102.39	99.10	3.29	0
Halton	856	22,336	1241	38.32	99.10	-60.78	1579
Hamilton-Wentworth	2478	38,376	1223	64.57	99.10	-34.53	1308
Metro Toronto	11,675	175,531	5634	66.51	99.10	-32.59	5837
Middlesex	2429	27,205	296	89.29	99.10	-9.81	179
Niagara	2932	36,309	555	80.75	99.10	-18.35	646
Ottawa-Carleton	2923	46,542	1142	62.80	99.10	-36.30	1313
Waterloo	1725	25,039	766	68.89	99.10	-30.21	814
York	1806	26,394	1014	68.42	99.10	-30.68	1523
Ontario	56,815	703,619	16,920	80.75	99.10	-18.35	20,000

Source: HSRC Reports, LTC Bed Distribution & Needs Study, 1996, MOHLTC Press Release, Nov. 19, 1998.

The implications of LTCF bed shortages include the backup of ALC patients in the acute care hospitals, a number of critical emergency situations in the community, and a number of retirement homes managing individuals at a level of care normally provided in a LTCF. Although there is funding available to facilities for equipment to support the complex care requirements of potential residents, they have difficulty with staffing availability and required skill sets. There is concern, too, that the pending changes in the number of chronic care beds will increase pressure on LTCF beds.

2.1b. Current Strategies

- The MOHLTC Regional Office is providing Staff support to the ALC Solutions Task Group, responsible for assessing strategies to facilitate the movement of ALC patients to appropriate destinations. Strategies being explored include:

    - Interim LTC bed opportunities including the use of space at Macassa and Wentworth Lodges, utilization of infirmary beds where appropriate
    - Implementation of a roster approach to balance LTC bed admissions from community and hospitals (Level 3 only)
    - Transitional care and flex bed opportunities on hospital sites
    - Continued/enhanced support for Quick Response Service

- Reassessment of ALC patient status in hospital
- Augmenting community resources with specialized expertise from hospitals

- The Joint Executive Committee is responsible for implementing the Health Services Restructuring Commission's directions for complex continuing care in Hamilton-Wentworth

- The Parliamentary Assistant to the Minister Responsible for Seniors, has initiated a "listening tour" to identify issues on the quality of care provided in retirement homes in Ontario. Services provided to retirement home residents at the level provided in a LTCF are a combination of CCAC services and services paid for privately by the client. This results in inequity of access to service and inequity in the financial impact on the residents.

2.2 HOUSING

2.2a Issue Identification

Previous LTC plans have indicated the need for more supportive and supported housing in the community. Currently, there are insufficient data on the level of need or priority needs. The volume of need in our community may be higher than expected as persons may move to Hamilton given the broad range of services available in the community.

Consumers have said:
- *There is a need for a greater range of housing services – more accessible family housing for rent, more funding to modify homes, higher standards for second level lodging homes, and more supportive housing units, group homes, segregated apartment, integrated apartments.*
- *There is a need for a range of health/support services available within senior's buildings*

A key issue is the increasing number of residents in seniors' housing who are getting more frail, and requiring more services, and/or a different approach to housing, in order to remain in their homes. A more flexible approach to service delivery – matching elements of a "basket of services" to individual clients' needs – may sustain people in their dwellings for as long as possible, prior to a move, for instance to a long-term care facility.

Consultations support the development of multi-level care settings. The multi-levels would include housing, supportive housing, retirement home and LTCF in a homelike setting, close to family, in neighbourhoods, with funding levels tied to access. This is consistent with recommendations long advocated by consumers. Current barriers to developing this type of setting include separate and diverse funding programs and funders, and diverse building code standards and care standards.

Previous ADSP and the MYP recommendations include:

- The Minister of Health approve funding for 17,830 - 18,230 additional hours of attendant care outreach services throughout the Region (97/97 ADSP, #1)
- The Minister of Health fund attendant care outreach to eliminate current waiting lists (98/99 ADSP, #A1)
- The availability and accessibility of attendant care services within the Region be ensured and that both self-managed and self-directed options for attendant care services be encouraged. (MYP #36)
- The CCAC and other providers of attendant care outreach consolidate intake processes and waiting lists, and develop protocols to ensure that clients receive attendant care outreach from a single provider agency (98/99 ADSP, #C1)
- The Minister of Health provide opportunities for direct funding of attendant care services.(98/99 ADSP, #A8)

Agencies have said:

- *The issues related to aging consumers and consumers with degenerative conditions has resulted in significant demand for increased attendant support, often beyond service or funding levels. Furthermore, creative support approaches and enhanced training for staff is often required.*
- *We would like to meet the changing needs of the frail elderly by providing "Assisted Living Suites" which offer security and companionship in a warm and friendly atmosphere by coordinating shelter, food, recreation, and support services that promote privacy, independence and the dignity of each resident. The major challenge here is providing this service to those whose income consists totally of basic pension and supplement. For these people, the services of the Assisted Living Unit will not be affordable.*
- *There is a need to prioritize supportive housing needs, to make sense of the sector*
- *There is a need for a residential hospice*

- The Minister of Health fund additional supportive housing units in Hamilton-Wentworth. (98/99 ADSP, #A7)
- The providers of supportive housing in Hamilton-Wentworth consolidate waiting lists and intake processes for supportive housing in Hamilton-Wentworth (98/99 ADSP, #C2)
- The Ministry of Health approve funding for the support of service facilitation in seniors' apartment buildings. (96/97 ADSP, #6)
- The Minister of Health expand the definition of supportive housing to include low-need housing for seniors such as the "Aging in Place" models. (98/99 ADSP, #A11)
- Social networks in neighbourhoods and apartment buildings where vulnerable Persons reside be promoted. (MYP, #50)
- Modern, appropriately designed residential and day care program facilities be developed for younger persons who are disabled. (MYP, #42)
- A comprehensive plan be developed in Hamilton-Wentworth to support people to live independently in their residences. (MYP, #33) The Plan must include:
  a) attendant care services
  b) meal services
  c) grocery shopping services
  d) home maintenance and home help services
  e) lifeskills programs, health education, and rehabilitation
  f) skilled and professional services
  g) retro-fit/home adaptation programs
  h) programs to provide a sense of safety and security (e.g. friendly visits), and

i) palliative care services.

Agencies were surveyed to determine the status and perceived relevance of the existing recommendations.

- Approximately $390,000 of attendant care outreach has been funded, more funding was pending until the current freeze. There is still a need for increased funding for attendant care outreach services. As of February 11, 2000, there was an estimated 90 individuals on the waiting list for attendant care outreach.[3]

- A comprehensive housing and related services plan to support people to live independently in their residences is required, inclusive of ageing in place models.

- Development of social networks for vulnerable populations is important based on the evidence of the benefits of social support networks, the development to be supported by a funded co-ordinator. The trend to neighbourhood based service management, (for example part of the CCAC RFP services are neighbourhood based) models some of this type of support.

- Some program reformation has occurred in order to create more attendant care outreach options, e.g. being responsive to emergency/night supports to individuals in accessible but undesignated housing units. Some attendant support programs use a self-directed model, and continue to work collaboratively with consumers to redefine/reform this model as necessary, e.g. those with impaired capacity, communication limitations, etc. For eligible individuals, there is a provincial self-managed/individualized attendant care option.

- A consolidated waiting list for attendant care outreach is being developed to monitor the number of individuals waiting for service at any one time.

- LTC supportive housing service providers meet regularly to discuss common issues, gaps in service, etc. They have produced a brochure, common intake form for supportive housing in H-W for seniors, persons with disabilities, and persons with HIV/Aids. It is not a coordinated service and there is no common waiting list.

2.2b Proposed Directions

HWDHC to develop a supportive housing plan in partnership with community stakeholders, which would include a review of the appropriateness of the current supportive housing policy and funding levels. The planning process should explore the potential development of residential settings which can provide multiple levels of care.

3 Discussion with Gayle Rivers, Participation House, February 14, 2000

The consultation process identified the following principles for the development of a supportive housing plan:

- *Policy needs to be inclusive and flexible to address a variety of models.*
- *The process should include the quantification of need for units and the required levels of service within those units.*

2.3 RESPITE, ADULT DAY PROGRAMS AND CAREGIVER SUPPORT

2.3a Issue Identification

Consumers have said they need:

- *support services for informal caregivers (family and friends), specifically respite, crisis intervention, workplace support, financial support – for supplies, equipment, and care provided*
- *societal recognition (particularly about caregiver stress and demands) and valuing of role of caregivers*
- *practical information available about caregiving approaches, self-care for caregivers, skills development, caring for the client, the disease itself*

Informal caregivers (family, friends, neighbours) provide unpaid, committed assistance to persons with in-home care needs and/or to persons who have functional limitations in carrying out their activities of daily living in the community. Caregivers may provide care on a continual basis, or may live in separate residences and provide part-time support. Although caregivers are not 'direct' consumers of long-term care services, their roles are increasingly recognized by planners, service providers, employers, and the general public. Caregivers are volunteers, and their gifts need to be acknowledged.

The demand for services and supports to caregivers is expected to increase. The largest group of care recipients are those aged 65 and over - a population segment which is expected to grow at an accelerated rate over the next 20 years. Ageing of caregivers, inadequate housing options, a shortage of paid staff, shift of care practices to community, and an increasing number of care recipients who are frail, ill and/or cognitively impaired[4] are all increasing caregiver burden.

Consumers have also said they needed:

- *An increased number of adult respite beds in the community*
- *Flexible respite option re: overtime, timely respite care*
- *Range of respite care: in-home, out-of home, planned and emergency, including access to short-stay beds*
- *Increased number of respite and short-stay options for children including medically fragile children More adult day programs (specifically those that cater to multiple types of clients and are located in rural communities)*
- *Adult day programs that offer secure settings, flexible days/hours which can accommodate caregivers' schedules*

The need for respite programs in Hamilton-Wentworth for all long-term care populations and age groups has been well documented by the District Health Council. Workshop participants reiterated the need for support and education for caregivers, the need for caregivers to be aware of the range of respite options early on in their caregiving experience, and the need for increased knowledge of medical problems, given shorter

[4]Central West Health Planning Information Network (1996). *Final Report on the Caregiver Support Services Study Completed in Central West.*

length of hospital stay. Health professionals too, particularly those in a position to make referrals, such as family physicians, need to be aware about what resources are available for caregivers.

All LTC populations/age groups need access to respite, and respite support may look quite different for different populations. For example, adult day programs for young disabled offer much more than respite. It's a "meaningful day", involving a connection to community and self-development. For children respite might look quite different. For example, some medically fragile children spend two days in the home, and then 2 days in the hospital. This planned, long-term strategy enables the families to cope and keep the child at home.

Agencies have said:

- *There is a lack of respite supports for families, children, and teens.*
- *TOP PRIORITY: Short term (hourly) respite in an appropriately designed community location – not available at present.*
- *Need for respite options without financial barriers.*

The capacity to integrate respite options is challenging as funding is connected to agencies, not the individual. A provincial pilot project underway in four communities may present some opportunities for service modeling. It is designed to better understand case management practices and the mix of services and supports required by medically fragile and technologically dependent children. This information will help in the redesign of the system of services for children with multiple special needs and their families. As well, the Ontario government announced $7 million in December 1999 to increase respite care for families caring for medically fragile or technologically dependent children at home. Eligible families will be able to purchase between 145 to 175 hours of additional respite care yearly, in addition to any other program funding that families are receiving.

The ADSP consultation identified the following elements as central to a community respite plan:

- supports that are "client centred" and "caregiver centred"
- measurement of service quality and the development of appropriate standards
- Access to respite across all LTC populations/age groups
- Financial, geographic and time of day accessibility
- a human resources strategy
- Inclusive of multiple options for service delivery – self-managed, regular planned, emergency and crisis prevention
- accountability
- inclusive of palliative care

Previous ADSP and the MYP recommendations include:

- Modern, appropriately designed residential and day program facilities be developed for younger persons who are disabled (MYP, #42)
- The Ministry of Health approve funding for 1620 to 2025 units of adult day services in Flamborough (96/97 ADSP, #2)
- The Minister of Health fund additional adult day program places to eliminate the waiting list. (98/99 ADSP, #A1)

- Funding for adult day services for persons with special needs, including persons with acquired brain injury, Alzheimer and cognitive impairment, be increased. (MYP, #40)
- Providers of adult day services develop and co-ordinate day programs for specific target groups.(98/99 ADSP, #C9)
- Day Service Providers assess the need for increasing hours of services. (98/99 ADSP, #C11)
- Adult day programs be distributed across the Region to reflect geographic distribution of need. (MYP, #41)
- Programs which increase awareness among the public, service providers and employers on caregiver issues and roles be developed and promoted. (MYP, #19)
- The range of flexible, integrated, affordable, specialized, and urgent respite options for caregivers and families be enhanced and include support for caregivers during holidays, weekends, evenings and nights, the removal of cost barriers to respite care, an increase in the number of adult respite beds in the community, and an increase in the number of respite and short-stay options for children including medically fragile children (MYP, #23)

Agencies were surveyed to determine the status and perceived relevance of the existing recommendations:

- Appropriate residential and day programs are required for younger disabled persons While some programs offer an integrated day service, usually focused on younger individuals with cognitive impairments, integrating young disabled individuals into existing programs is a challenge.

- $47,345 was allocated from the Hamilton-Wentworth funding envelope to adult day programs in Flamborough. While areas within the city remain unserviced (e.g. West Mountain, Stoney Creek, Mt. Hope, etc.), geographic distribution may not be cost-effective, as programs have different, unique features which do not at this time support a geographic plan. Client choice remains the primary consideration.

- Significant effort has been taken to centralize access and to develop a centralized waiting list (at CCAC). This will clarify demand/need, service providers will be able to efficiently identify service gaps in service delivery, and trends/projections of needs will be monitored.

- Extended hours are difficult to provide. Client numbers may be smaller for extended hours and funding does not adequately support the standard of two staff available at all times. The need for extended hours may grow as sandwich generation caregivers grow in numbers.

- Approximately $72,000 was recently allocated for increased adult day services for persons with dementia.

- Regional adult day program plan required addressing number of sites, locations, day service spaces, and special service needs with consideration for a neighbourhood model approach

- A funding model for adult day programs that reflects differing levels of client acuity and related services is required. Three agencies have attempted to respond to the need for

dementia-specific programs. However, need for specialized service exceeds program availability and specific areas within the city remain unserviced. Standards and criteria for integrated and specialized services need to be defined.

- Coordinated provider approach required for goal of increasing awareness on caregiver issues and roles. The new position of Education Coordinator at the Alzheimer's Society is funded to raise awareness of dementia in the community. An inventory of existing services needs to be developed.

- Flexible models required for people who cannot afford respite and caregiver relief and who don't qualify for public funding. More needs to be done, "This is an absolute priority".

2.3b Proposed Directions

HWDHC to develop a respite plan in partnership with community stakeholders.

The consultation process identified the following principles for the development of a respite plan:

- *Funding needs to be "client centred" and "caregiver centred"*
- *All LTC Populations/age groups need access to respite*
- *There need to be multiple options for service delivery – self-managed, regular planned, emergency and crisis prevention*
- *There needs to be flexibility between options and within options*
- *Respite needs to be accessible*
- *The system needs to be accountable*
- *The system needs to include end-of-life respite care*

2.4 TRANSPORTATION

2.4a Issue Identification

Consumers have said they need more/expanded accessible and available public and volunteer transportation (especially in rural communities)

Transportation options support peoples ability to access required health and social services, and remain connected to their communities. Transportation planning for LTC clients is challenging, as most of the formal service provision is managed outside the LTC Community and Facility envelopes, indeed outside the MOHLTC. Transportation options include the Disabled and Aged Regional Transportation System (DARTS); private taxi companies using a mixed fleet of taxis and adapted vans; low floor Hamilton Street Railway buses; volunteer assisted transportation, and the elective patient transport service. A few agencies assist clients in accessing their programs through their own transportation programs. There is not an overall transportation strategy for these populations/programs.

Agencies have said:

- *Outlying areas are witnessing a large influx of retirees with few services to meet their needs, thus transportation options will be needed.*
- *Assisted transportation is needed for consumers who do not have a visible impairment but are unable to travel independently, e.g. those with a dementia.*
- *Recognition that volunteer transportation is provided by volunteers and therefore is limited to their availability, skills and willingness to accommodate.*

Volunteer drivers are becoming increasingly difficult to recruit, for reasons including a limited available pool (largely retired persons available during the day), liability insurance costs, gas costs, and the higher level of complexity and need of clients.

At the same time, demand for volunteer assisted transportation and DARTS services is increasing with changing demographics and increased reliance on community based care and outpatient therapies. Challenges to service provision and client satisfaction include geographic coverage across the Region, the cost of the taxi script system, the length of time required by DARTS for notice of trip, and 12 hour bookings for medical treatment appointments. The lack of appropriate transportation options puts consumers at risk of social isolation and impacts on families who depend on transportation for respite programs.

Two committees in the community address transportation issues. One is the Providers of Volunteer Assisted Transportation, and the other is the Adult Day Services and Transportation Group. As of January 2000, the Providers of Volunteer Assisted Transportation Group has disbanded.

Previous ADSP and the MYP recommendations include

- That the health sector work closely with the social service sector to develop an integrated transportation system that makes effective use of all resources including ambulance transfer services, parallel transit, volunteer assisted transportation, and school transportation. (MYP #54)
- That the Regional transportation plan be developed to ensure a positive impact on the community's health. (MYP, #55)

Agencies were surveyed to determine the status and perceived relevance of the existing recommendations. The need for the development of a Regional transportation plan was reiterated.

2.4b Proposed Direction

HWDHC staff to review the Regional Transportation Master Plan, the activities of the Regional Transportation Committee, and the recommendations of the Regional Progress Team to summarize what initiatives and recommendations currently exist in the area of transportation initiatives for LTC populations.

2.5 HUMAN RESOURCES

2.5a Issues Identification

Consumers have said they would like continuity of staff

Responsive programs and services for long term care populations need to be linked to human resource strategies to adequately support service delivery. The ADSP workshop consultations identified issues around three health human service resource groups; professionals (nurses and therapists), personal support workers and volunteers. The problems identified are largely a lack of funding compounded by scarcity of health human resources. Agencies have refused referrals because they don't have the available staff. Consumers have identified that the RFP approach has impacted on the continuity of care they experience.

The scarcity of staff is a local and provincial issue. There is large variability in wage scales and working conditions among health care provider groups, and between hospitals and other community based services.

Agencies have said:

- *We need standards of care for non-regulated personal support workers.*
- *There is a human resource crisis -*
- *There is inadequate funding to hire and maintain skilled staff.*
- *Staff shortages are contributing to staff burnout and staff turnover.*
- *There is competition among agencies for volunteers vs. a coordinated approach (causing waiting lists for services).*
- *The present volunteer base is aging, new volunteers are difficult to recruit and the cultural/language recruitments are increasing as the population changes.*
- *There is insufficient staffing in LTCF to effectively carry out complex care plans.*

Personal Support Workers (PSWs)

The current PSW education program prepares its graduates to work in the community, in LTCF, and in certain hospital positions. As wages in the LTCF and the hospitals are significantly higher – $5 to $6 more per hour - and working hours are more structured, there is great difficulty in attracting and keeping PSWs in community-based services. The staffing requirements of the new LTCF will exacerbate the supply issue. Workers have identified that working in the community can also be more stressful, as there is often less backup, and no on site support. These factors make it difficult for the community agencies to compete for limited numbers of workers.

Professional Staff

Professional staff include nurses, physiotherapists, occupational therapists, speech language pathologists, social workers and nutritionists. Currently there is a significant provincial shortage of nurses and speech language pathologists, but physiotherapists and occupational therapists can also be hard to recruit, as hospital and private sector opportunities are more lucrative. Both the shortage of nurses and the difficulty in retaining nurses in the community based service sector affect the availability and continuity of care. Managed competition has lowered community based nurses salaries relative to other sectors. The CCAC is signing longer-term contracts for nursing and homemaking services, which should assist with recruitment and retention of staff.

Volunteers

Volunteers play a significant role in the long-term care service sector. Volunteer provided services include transportation, food delivery, visiting, and telephone reassurance services. It is difficult to estimate the financial burden on the long-term care service sector if the funding envelope was required to replace the services of volunteers.

Challenges to volunteer supply include:

- Changing demographics: existing volunteers are aging and new retirees are not volunteering in the same numbers or in the same way. This has led to competition between agencies for volunteers.
- Changing Expectations: Research suggests that volunteers seem to be interested in shorter-term projects and more skills focused opportunities[5] hence the interests of the volunteers may not match the current needs of the agencies.
- Recruiting, coordinating and training volunteers, and recognizing volunteer contributions, require volunteer management professionals with adequate resources

On the demand side, the recipients of volunteer services are culturally diverse, inclusive of newcomers and refugees. This diversity is not always reflected in the volunteer workforce.

Previous ADSP and the MYP recommendations include:

- The long-term care system develop a co-ordinated approach to volunteer development which strives to:
  a) recognize volunteers as valued team members
  b) attract a range of volunteers who can meet needs in diverse geographic, ethno-cultural and linguistic communities
  c) recognize and respect volunteers motives in offering their services
  d) provide training and support as required
  e) strengthen and evaluate training programs for volunteers; and
  f) ensure appropriate resources to support the development and recognition of volunteers (MYP, #53)

- Providers of community long-term care programs and services build strategic alliances to support ongoing recruitment and training of volunteers. (98/99 ADSP, #C19)

Agencies were surveyed to determine the status and perceived relevance of the existing recommendations.

- The continued development, support and recognition of volunteers is a high priority and should be supported with additional resources.

5 Discussion with Liz Weaver re the 1997 Volunteer Survey

- The Volunteer Centre is providing a range of services to member agencies to assist with training and recruitment of volunteers. Individual agencies are doing this, often in partnership with other agencies, but are not aware of a coordinated system approach. The continued development, support and recognition of volunteers is a high priority

- 2001 is the International Year of the Volunteer.

2.5b Proposed Direction

HWDHC to invite the Volunteer Centre to take a lead role in bringing together LTC community agencies, consumers, volunteers, the Ministries of MCSS, MOHLTC, Citizenship and Recreation, and the Regional Municipality to develop a community marketing strategy to enhance volunteer recruitment.

2.6 INTEGRATED SERVICES

2.6a Issue Identification

Long-term care consumers and providers experience a fragmented service system which can impede timely and appropriate access to required services.

Consumers often experience long-term care services as a set of distinct agencies with whom they establish discrete client/provider relationships. This experience is often echoed by front-line staff who don't have the mechanisms in place to support their knowledge of the service system which in turn supports their work with consumers and other agencies in the care path.

Agencies have said:

- *There is a need for a forum which brings together providers from various sectors to plan an integrated system and breaks down current provider silos.*
- *How to offset the loss of collaborative efforts with other service provider groups in the community due to competition for contracts.*
- *Ongoing meaningful consumer influence on decision-making*
- *Advocacy/service support for LTC clients who are "messy" – i.e. not compliant, involved with the public trustee, sometimes have mental health, housing/landlord issues*
- *Need for enhanced linkages between sectors*
- *MCSS, LTC, MOHLTC working independently. Many new excellent Too many "single" points of access – CCACs, Contact Hamilton-Wentworth, Early Words, Day Care Community, Integrated Resources HUB, and sometimes the same child or children. What does single point of access mean?*

Recent ADSP consultations cited numerous examples of system fragmentation:

- Response times of community based services for patient requirements following hospital discharge are not keeping pace with trends in weekend discharge practices and off hour referrals

- The impact of shorter lengths of hospital stay for some consumers is user fees for services/supports in the community that may have been included in their hospital care. The process for getting and paying for these drugs and/or lab tests in the community may be complex, and requires coordination between services/sectors.

- Informatics infrastructure to support sharing patient information and system monitoring and evaluation are not fully in place.
  - Primary care physicians need to be advised of their patients' movement across the system – from community to hospital, hospital to LTCF or home, so that they can respond to care requirements in a timely way. For instance, drugs given in hospital can impact on clients in ways different from their pre-hospital experience; antibiotics can impact on blood coagulation, and clients managed pre-hospital on bi-weekly testing may now need twice a week testing.
  - Different information reporting requirements between and within Provincial ministries, the lack of a uniform minimum data set, and the lack of a common framework for describing the activity undertaken, i.e. Case Mix Group, patient service group, unit of service. Lack of strategic direction at the Provincial level is played out at the local level where agencies are not using compatible software programs, developing common assessment tools, and implementing strategies for sharing information.

- The pace of change in the acute care sector and decisions taken made are not always shared with the community. For example, the decision to reduce the availability of a hospital-based palliative care outreach team was made in isolation from stakeholder community agencies and individuals.

- Planning for services, especially children's services, is very fragmented. Multiple funders with multiple criteria for programs can make it difficult for parents, as well as agency staff, to provide integrated service to children.

Consumers have said:

- *We want to be involved in the planning of coordination of services since we are the 'experts'; the role of the service provider is to use his/her skills to facilitate and support the individual to achieve the fullest possible integration with support services*
- *There is a need for greater integration and coordination within and among children's LTC services and other sectors including recreation, education and social services. There is also a discontinuity of services from adolescence to adulthood, and a gap in service between ages 16 and 18 years*
- *We want a common system of information, referral, assessment, and placement which is easily accessible*
- *Better inter-agency collaboration, communication, coordination, planning*
- *service providers need education/awareness of caregiver challenges, and information on how to link client to inform caregiver of available options and services, information on how to foster inter-services coordination*

Some examples of initiatives to address service fragmentation and promote service integration include:

- "Blueprint for Planning, Development and Implementation for Seniors Health in Ontario", supported by the Regional Geriatric Programs of Ontario, the Ontario Interdisciplinary Council on Aging and Health, the Ontario Inter-Faculty Geriatric Psychiatry Group, as well as invited experts from Community Care Access Centres and Long-Term Care Facilities. The principles which are being suggested to guide the blueprint include: client/individual at the centre of the system; access to services that are streamlined; services

that are linked and co-ordinated so that citizens are able to move easily from one part to another; services that are tailored to need; services that are based on best practices.

- The Children's Treatment Centre has developed and implemented a Windows Based Client Information System, WinCIS. Information can be utilized for many purposes. A clinical screening interview (content and process) is being piloted for clients who present with developmental behavioural and emotional problems. The Centre has also supported the development of the Preschool Speech Language Planning Regional Access process and software development.

- There are a number of groups/committees working on enhancing service coordination. They include, among others: the Coalition of Community Health and Support Services, a number of ministry supported working groups on improving protocols, etc., a number of sector specific committees such as Food Access, Volunteer Assisted Transportation, etc., and the Specialized Health Care for the Elderly Program

Recommendations in previous ADSP's and the MYP include:

- Protocols to ensure communication and co-operation among and within sectors of the health and social service system be developed and mandated. (MYP, #13)
- Accountability mechanisms to ensure that all partners in the LTC system, including clients, comply with their agreed upon role and responsibilities be developed, communicated, and sanctioned among all partners in the long-term care system. (MYP, #10)
- The LTC system support initiatives to develop a system of information management which:
  a) is responsive to community members, planners and providers for system planning purposes;
  b) is responsive to clients and their resource facilitators (case managers) to make client-directed plans;
  c) supports client assessments that are timely, relevant, and standardized;
  d) safeguards confidentiality and protects clients rights;
  e) promotes quality improvement;
  f) supports relevant and integrated client records that conform to commonly understood terminology;
  g) uses appropriate filters to screen information; and
  h) is recognized across various sectors of the integrated health system. (MYP, #16)

Agencies were surveyed to determine the status and perceived relevance of the existing recommendations.

- Many agencies are working with others on particular communication/cooperation projects, including broad coalitions and working groups. Some particular initiatives include the development of a Flamborough branch office of a number of agencies, enhanced communication and protocol development with the CCAC, secondment of staff between agencies, and development of intersectoral children's initiatives.

- Universal Patient Transfer Forms have been developed to enhance effective communication among hospitals and long term care facilities. Partnerships between the lodges and chronic and acute care hospitals are increasing; mental health and behavioural interventions are two examples.

- Social support service groups collaborate well at the planning level; however, there are not the structures to facilitate this at the client level. While there appears to be a willingness to utilize universal assessment tools across acute care, LTC and community, the tool does not yet exist.

- Agencies are working on the development of information management systems, both internally and in partnership with others. Both the OCSA draft Standards Criteria Guidelines for Good Practice and Indicators for Selecting Community Support Services and the Guidebook for the Evaluation of the Quality of Services Provided by Community-based LTC agencies developed by Halton-Peel DHC April 99 will assist in a more standardized approach to service delivery and evaluation. HWCCAC now holds regular quarterly meetings for service providers to collaborate on these types of initiatives. The Coalition of Community Health & Support Services is in the process of applying to the McLaughlin Centre for research funding to look at many of these issues for community-based services.

- CCAC Information & Referral development proceeds slowly. IT system support was withdrawn by the province and a new initiative is underway.

- A partnership between CIS Hamilton, Dundas Community Services, Ancaster Information Services, Flamborough Information & the Hamilton Public Library has been established and they are mounting their web based collective human services database.

2.6b Proposed Directions

HWDHC undertake a community mapping of LTC services.

HWDHC's staff should develop and update a listing of planning and coordinating groups in Hamilton-Wentworth.

The Ministry of Health and Long-Term Care support the development of a Minimum Data Set and the infrastructure required to support the local development of a system of information management.

2.7 HOW WE DELIVER SERVICES

2.7a Issue Identification

ADSP consultations confirmed the need for long term care programs and services to be responsive to the diverse communities of Hamilton-Wentworth. This includes the need to develop a welcoming environment for diverse individuals, as well as the appropriate supports to provide services. Diversity is broader than language and culture, and includes such issues as poverty, and mental illness.

Consumes have said:

- *We want individualized, flexible, non-intrusive physical, cognitive and behavioural interventions/services that maintain the person's dignity and self-worth*
- *Stop developing programs for people that keep them dependent, but start looking for ways to help individuals take informed risks (role shifting from promoting dependence to teaching independence)*
- *A vision for a healthy community for persons with a disability which includes more individual control over funds, availability of housing and support services, support in accessing and retaining employment, adequate income, economic security, a need for adequate safety and security needs to be developed and acted upon.*
- *emphasis on family-centered care, involving the family in decision-making, service planning and care*
- *clients and caregivers to determine the rhythm of care (especially in the home);shift from service needs to client needs*
- *provision of culturally sensitive care in a welcoming environment*

A welcoming environment is accessible and includes flexible service delivery. Some of the barriers to an accessible environment can include age, attitude, cognitive/developmental status, education, employment skills, finances, geography, and literacy. Success factors for welcoming environments include available community expertise around such issues as culture, language, religion, and mental health issues, a shared definition of family centered/personalized care, educated front-line staff, and applied evaluation and monitoring tools.

Hamilton-Wentworth has a diverse population with many ethnic groups represented. Eighteen percent of residents have a first language other than French or English. The cultural diversity of the community challenges agencies to offer services that are culturally accessible.

Population by Mother Tongue for Hamilton-Wentworth – 1996

Mother Tongue	Population	% of Total Population
English	349,460	76.6%
Italian	21,505	4.7%
Polish	9,135	2.0%
Portuguese	7,360	1.6%
French	7,050	1.5%
German	6,530	1.4%
Others	55,020	12%
Total Population	456,060	100.0%

Source: HWDHC Operating Plan, 1999/2000

Hamilton-Wentworth is diverse in other ways as well. The number of people in poverty is increasing in Hamilton-Wentworth. This increase places demands on agencies in two ways. Firstly, individuals may need assistance with accessing basic services, and secondly, they may be unable to purchase some of the additional support services they may need, such as home repair, or additional homemaking.

Agencies have said:

- *We are seeing an increasing number of elderly males with health-related concerns at our hostel for men. These men require assistance with accessing medical services and need the reassurance checks offered by the hostel staff.*
- *Specialized target groups require research and planning to address their short and long-term needs.*
- *It is difficult to find volunteers with the necessary language skills and cultural background to visit those with specific language/cultural needs.*
- *Many consumers report living in conditions of poverty, often inadequately housed and relying on essential community supports (e.g. food banks) for survival. In addition, poverty often prevents adequate integration within the community. This is particularly true when considering the shortage of attendant outreach or affordable, supportive housing.*

Historically there have been concerns about the availability of home care services to those individuals with mental health problems. These clients can be quite challenging for staff without specialized training. With the recent change in the provincial regulations limiting care to those requiring personal care this situation may be exacerbated. The Hamilton-Wentworth CCAC is not currently using the requirement for personal support as exclusionary criteria for service provision.

The populations considered to be joint clients of both mental health and LTC services include[6]:

- Older people who have behavioural disturbances and/or mental health problems associated with cognitive impairment
- Older people with mental health problems with medical illness and/or functional needs
- Older people with severe mental illness, including those who require acute and ongoing mental health care as well as services provided by the long term care network, and older people with long-standing severe mental illness who require complex care and/or have functional limitations
- Older people who develop severe late-onset mental illness (e.g. depression)

Recommendations in previous ADSPs and the MYP include

- Cultural and linguistic sensitivity be promoted through the development of:
  a) education programs for staff and volunteers working with diverse populations
  b) policies which remove discriminatory barriers and ensure accessibility; and
  c) outreach initiatives to promote the accessibility and visibility of programs and services to diverse groups (MYP, #2)
- Providers of community long-term care services develop partnerships with ethno-cultural communities, advocacy groups, client populations, and caregivers to meet the care needs of diverse populations (98/99 ADSP, #C20)
- Both public and private sectors in the community be required to adopt and implement recognized standards of accessibility That both public and private sectors in the community be required to adopt and implement recognized standards of accessibility. (MYP, #5)

6 Stakeholder Forum on Psychogeriatric Services in Grey Bruce Huron and Perth, Final Report, September 1999

- Programs promoting, nurturing, and valuing family and community diversities be supported and developed. (MYP, #1)
- The DHC request the "identified" LTC funded agencies to submit their French language service implementation plans to the DHC for review in 1996. (96/97 ADSP, #8)

Agencies were surveyed to determine the status and perceived relevance of the existing recommendations.

- The issue of enhancing cultural and linguistic sensitivity is still relevant. Many agencies have or are developing anti-racism policies, programs and plans, without funding or a community plan. United Way has provided anti-racism workshops and is mandating United Way funded agencies to have an anti-racism policy.

- Agencies felt increased funding should be made available for translation and interpreter services to ensure that the needs of non-English speaking clients are met appropriately.

- No French language service implementation plans have been submitted to the HWDHC for review, however, many agencies are working on developing their capacity to provide services in French. Many agencies also have materials available in French. French language training is available through the MOHLTC.

- Some agencies have initiated particular projects, e.g. Shalom Village Bistro is an accessible kosher restaurant open to the community; the Regional Municipality established an Advisory Committee for Immigrant & Refugee Issues in May 1999.

- Unfortunately, accessibility for individuals with a visual or a hearing impairment is not usually considered under the access umbrella.

- Some organizations are encouraging employment applications from various multicultural organizations, e.g. posting positions at sites.

- Some providers have begun developing partnerships with ethno-cultural communities advocacy groups, client populations, and caregivers. However, when resources are short this kind of activity is not given the attention it deserves. Members of ethno-cultural communities and groups need to be part of the consultation and planning processes to ensure agencies learn how well they are responding to the health and social support needs of their diverse clientele.

- There is no funding for program sustainability for programs promoting, nurturing, and valuing family and community diversities. However, many services are personalized and participant directed therefore they fairly adequately target diversities and personalized needs.

2.7b Proposed Direction

The HWDHC work with the community on identifying the elements of a welcoming environment.

3.0 CONCLUSION

The approach of this Annual District Service Plan was to identify a limited set of directions based on previous reports, consultations and activities. The focus is to develop a more strategic workplan, which will allow the HWDHC, the MOHLTC, and the community to focus on a smaller set of issues and develop more focused plans.

APPENDIX A

SUMMARY OF CONSUMER AND AGENCY COMMENTS ON IDENTIFIED DIRECTIONS

SUMMARY OF CONSUMER VIEWS ON HOUSING IDENTIFIED IN EXISTING COMMUNITY REPORTS

- Need for a greater range of housing services – more accessible family housing for rent, more funding to modify homes, higher standards for second level lodging homes, and more supportive housing units, group homes, segregated apartment, integrated apartments.
- Wide variety/flexible range of housing options including profit and not-for profit housing, granny flats, renovations in private homes, secured or locked units for clients with special needs
- Appropriate structural and physical environments that are safe, and cater to multiple types of clients
- Range of health/support services available within senior's buildings

SUMMARY OF AGENCY SURVEY RESPONSES TO IDENTIFYING CURRENT SERVICE CHALLENGES AND ISSUES RELATED TO HOUSING

- A large number of individuals with severe, long-term needs related to their ABI are applying for admission to the ABI supportive housing unit dedicated to providing 24 hour support to this population. There will be no vacancies in existing services for many years.
- There is need for supportive housing for individuals who have a cognitive impairment, and need on-site call capabilities
- The issues related to aging consumers and consumers with degenerative conditions has resulted in significant demand for increased attendant support, often beyond service or funding levels. Furthermore, creative support approaches and enhanced training for staff is often required.
- We would like to meet the changing needs of the frail elderly by providing "Assisted Living Suites" which offer security and companionship in a warm and friendly atmosphere by coordinating shelter, food, recreation, and support services that promote privacy, independence and the dignity of each resident. The major challenge here is providing this service to those whose income consists totally of basic pension and supplement. For these people, the services of the Assisted Living Unit will not be affordable.
- The population in seniors housing is at different ages and stages of ability. Some will be able to remain in their apartments if they receive support services such as home cleaning and laundry. The challenge is to provide these services to those who do not qualify for services through the CCAC. They are the ones who will have to leave because they cannot perform housekeeping tasks or cannot afford to pay the market rate for such services. There is planning for a menu of services which will enable residents with varying support needs to afford a "package" of services. This will be possible because the numbers in the complex will allow for "clustering" of services.
- The final challenge is maintaining an on-site coordinator for an aging in place model now that funding has been removed. The need for the services offered through this position has never been more acute. Contributing to this need is the early discharges from the hospital, the increasing difficulty to access services through Long Term Care, the stringent qualifications required to enter a Long Term Care facility, and the ever-decreasing abilities of those who reside in seniors housing.
- Need to prioritize supportive housing needs, to make sense of the sector
- Need for a residential hospice

SUMMARY OF CONSUMER VIEWS ON RESPITE PROGRAMS IDENTIFIED IN EXISTING COMMUNITY REPORTS

- More adult day programs (specifically those that cater to multiple types of clients and are located in rural communities)
- Adult day programs that offer secure settings, flexible days/hours which can accommodate caregivers'schedules
- Adult day programs specifically located in Ancaster and West Mountain for cognitively impaired adults
- Support services for informal caregivers (family and friends), specifically respite, crisis intervention
- Peer support groups and buddy systems for disabled adults and their caregivers
- Parent support groups
- Informal support for caregivers, e.g. mutual aid and advocacy groups
- Counselling support for caregivers (emotional, psychological and spiritual)
- Workplace support for caregivers
- Financial support/compensation for caregivers – for supplies, equipment, and care provided
- Societal recognition (particularly about caregiver stress and demands) and valuing of role of caregivers
- Support for caregivers, especially during holidays, weekends, evenings and nights
- Assistance with personal care, safety, household management for caregivers
- practical information available about caregiving approaches, self-care for caregivers, skills development, caring for the client, the disease itself
- easily accessible information about the range of available services, caregiver support services, etc., in one place
- service providers need education/awareness of caregiver challenges
- service providers need to have information on how to link client to/inform caregiver of available options and services, information on how to foster inter-services coordination
- Increased number of adult respite beds in the community
- Flexible respite option re: overtime, timely respite care
- Range of respite care: in-home, out-of home, planned and emergency, including access to short-stay beds
- Increased number of respite and short-stay options for children including medically fragile children

SUMMARY OF AGENCY SURVEY RESPONSES TO IDENTIFYING CURRENT SERVICE CHALLENGES AND ISSUES RELATED TO RESPITE

- Need for respite care and care giver support.
- Lack of respite supports for families, children, and teens.
- TOP PRIORITY: Short term (hourly) respite in an appropriately designed community location – not available at present.
- Need for respite options without financial barriers.
- Therapeutic recreation programs for all persons with dementia, living in the community, retirement homes or LTCF (latter not available), especially middle-aged men and women.
- To provide the continuum of services required throughout the course of the disease for persons with dementia and their families, who are increasing in numbers and whose needs are more complex. Family caregiver "hardiness" can only be achieved by a range of flexible, timely, accessible support and respite programs.
- Additional respite beds (in secure settings) throughout the community for more frequent admissions during the year.

SUMMARY OF CONSUMER VIEWS ON TRANSPORTATION IDENTIFIED IN EXISTING COMMUNITY REPORTS

- More/expanded accessible and available public and volunteer transportation (especially in rural communities)
- Accessible and affordable transportation for clients and caregivers

SUMMARY OF AGENCY SURVEY RESPONSES TO IDENTIFYING CURRENT SERVICE CHALLENGES AND ISSUES RELATED TO TRANSPORTATION

- Outlying areas are witnessing a large influx of retirees with few services to meet their needs. Provision of services in communities assists residents to remain in their homes and reduces demand on transportation services.
- Transportation for consumers who do not have a visible impairment but are unable to travel independently, e.g. dementia. Transportation Coordinator of transportation services?
- DARTS for person with dementia requires trained drivers.
- Volunteer recruitment and retention for transportation programs
- Recognition that transportation is provided by volunteers and therefore is limited to their availability, skills and willingness to accommodate.
- Accessible transportation which is flexible and responsive is the single most mentioned concern by consumers.
- Improvements in the transit system have been acknowledged, particularly the accessible buses, however feedback suggest that DARTS is not able to adequately meet the needs of the disabled.

SUMMARY OF CONSUMER VIEWS ON HUMAN RESOURCES IDENTIFIED IN EXISTING COMMUNITY REPORTS

- Would like continuity of staff
- more education and training for service providers is needed, particularly regarding the management of behavioural problems and issues

SUMMARY OF AGENCY SURVEY RESPONSES TO IDENTIFYING CURRENT SERVICE CHALLENGES AND ISSUES RELATED TO HUMAN RESOURCES

- Difficulty recruiting and retaining qualified RNs and RPNs – funding base does not allow us to offer salaries/benefits competitive with the acute care sector
- Staff feel vulnerable due to instability – will we have our contract renewed every three years?
- Difficulty maintaining adequate staff resources to train and monitor volunteers. With the increasing number of seniors needing the service, there is a corresponding increase in the number of volunteers required.
- Difficulty in recruiting volunteers from the community. This is a very necessary component of the program because diversity is required for successful matching.
- To ensure an education component is available for volunteers. It is important that the volunteers feel part of the team and know they are supported. This is achieved by providing them with knowledge and training at in-service workshops. They also experience support from their peers at these education days.
- Standards of care for non-regulated personal support workers.
- Human resource Crisis – severe shortage of Homemakers/PSWs. LTC facilities paying $5 more an hour. Opening of LTC beds next year will exacerbate crisis. Refusing referrals regularly. Turnover rates have gone up and holding at 24%. (We have benefits, pension plan, pay travel expenses, and have competitive community wages.)
- Complexity of care is increasing – "nursing" tasks being performed by PSWs. A rising risk of liability to agencies and increasing costs related to supervision of delegated tasks, without any recognition of need for increasing unit costs.
- Discontinuity of care in regards to managed competition and changing providers. This uncertainty and lack of security is also driving up as staff seek more secure employment elsewhere.
- Staffing issues – inadequate funding is provided to hire and maintain skilled staff.
- Staff shortages are contributing to staff burnout and staff turnover.
- Lack of volunteers to appropriately deliver service – competition among agencies for volunteers vs. a coordinated approach (causing waiting lists for services).
- Some of our limitations related to service provision could be eased with a well-supervised and trained roster of volunteers. BISH requires minimal funding to operate a quality volunteer program.

SUMMARY OF AGENCY SURVEY RESPONSES TO IDENTIFYING CURRENT SERVICE CHALLENGES AND ISSUES RELATED TO HUMAN RESOURCES, cont'd

- Volunteer Recruitment – Volunteers are looking for shorter term commitments but this service benefits with long term commitments. The present volunteer base is aging, new volunteers are difficult to recruit and the cultural/language recruitments are increasing as the population changes. The results are increased costs associated with recruitment, training and retention of volunteers.
- The RFP approach is contributing to inconsistent care, uncertainty of who provider will be in the long run.
- Insufficient staffing in LTCF to effectively carry out complex care plans
- Ministry of Health does not recognize the existing salary and wages when providing funding envelopes to LTCF
- Maintaining/recruiting highly skilled staff who are able to competently respond to greater client care requirements and specialized service needs (i.e. Alzheimer's, catheter care, table feedings, etc.). Ensuring wages are equitable with other service providers (i.e. hospitals, regional homes, etc.) to keep and attract staff.
- Difficulty in recruiting and retaining volunteers for transportation programs
- Recognition that transportation is provided by volunteers and therefore is limited to their availability, skills and willingness to accommodate.

SUMMARY OF CONSUMER VIEWS ON INTEGRATED SERVICES IDENTIFIED IN EXISTING COMMUNITY REPORTS

- Discontinuity of services from adolescence to adulthood, and a gap in services between ages 16 and 18 years
- Clients want to be involved in the planning of coordination of services since they are the 'experts'; the role of the service provider is to use his/her skills to facilitate and support the individual to achieve the fullest possible integration with support services
- Disabled adults do not feel they are being adequately accessed for planning, developing, coordinating and providing services, thus services often don't match their needs or access their skills
- Would like enhanced continuity of care: service providers working as a team
- Need for greater integration and coordination within and among children's LTC services and other sectors including recreation, education and social services
- Coordinated service delivery to: ensure flexibility; disseminate information; link physicians and others who play the role of gatekeepers to services; provide case management
- Improved transitions for consumers through life cycle and/or different levels of services
- Improved communication and information sharing mechanisms
- Common system of information, referral, assessment, and placement which is easily accessible
- Better inter-agency collaboration, communication, coordination, planning
- Too many people involved in providing services and there is not one person/organization overseeing what is happening. Need single agency who coordinates information and services
- service providers need education/awareness of caregiver challenges, and information on how to link client to/inform caregiver of available options and services, information on how to foster inter-services coordination

SUMMARY OF AGENCY SURVEY RESPONSES TO IDENTIFYING CURRENT SERVICE CHALLENGES AND ISSUES RELATED TO INTEGRATED SERVICES

- There is a need for a forum which brings together providers from various sectors to plan an integrated system and breaks down current provider silos.
- How to offset the loss of collaborative efforts with other service provider groups in the community due to competition for contracts.
- Enhanced coordination – ensure the clients who need the services are getting them, not just who shows up
- Ensuring that protocols procedures that have been collaboratively developed with the service providers are working to effectively manage the Central Wait List and access for services. To ensure the change in process is communicated to our traditional referral sources and the general public.
- Eliminate duplicate administrative assessments
- Better coordination between CCAC and community supports
- How do we hold the RFP accountable to community needs and priorities
- Ongoing meaningful consumer influence on decision-making
- Advocacy service support for LTC clients who are "messy" – i.e. not compliant, involved with the public trustee, sometimes have mental health, housing landlord issues
- Enhanced coordination between mental health and LTC, needs to be broader than the LTCF
- Need for enhanced linkages between sectors
- MCSS, LTC, MOHLTC working independently. Many new excellent initiatives but insufficient planning re data design, accountabilities, etc., which require large resources from children's treatment centres and utilize needed front line staff as well as increase legal and audit costs and contract signing.
- Too many "single" points of access – CCACs, Contact Hamilton-Wentworth, Early Words, Day Care Community, Integrated Resources HUB, and sometimes the same child or children. What does single point of access mean?

SUMMARY OF CONSUMER VIEWS ON HOW WE DELIVER SERVICE IDENTIFIED IN EXISTING COMMUNITY REPORTS

- Individualized, flexible, non-intrusive physical, cognitive and behavioural interventions/services that maintain the person's dignity and self-worth
- Supports and services should be tailored to individual needs and be transferable from location to location so individuals can access a range of options for future living arrangements
- Stop developing programs for people that keep them dependent, but start looking for ways to help individuals take informed risks (role shifting from promoting dependence to teaching independence)
- Services should be more holistic, functionally oriented and available in the community whenever possible
- Overall services should be responsive, coordinated, accessible, comprehensive, accountable and cost-effective
- Want to maintain individual responsibility and personal control over the delivery of services
- Require a comprehensive initial assessment to ensure appropriate service referrals and on-going periodic re-assessments
- Want services providers/assessors who know the system and understand the needs of people
- A vision for a healthy community for persons with a disability which includes more individual control over funds, availability of housing and support services, support in accessing and retaining employment, adequate income, economic security, a need for adequate safety and security needs to be developed and acted upon.
- Independent living, functional living and life skills training – empowerment oriented services
- contact with service providers that are courteous and respectful
- service providers take a holistic approach to service delivery
- emphasis on family-centered care, involving the family in decision-making, service planning and care
- (Simplified) access to information that is central, well publicized and tied to advocacy. Information and public education about the range of services available, how to access them, where and how to get help, the disease itself
- information and public education about specific problems, i.e. elder abuse and self-neglect
- outreach initiatives to promote the accessibility and visibility of programs and services to diverse groups
- information that is designed to meet the different needs of different client groups
- service providers should provide choices and information to clients so they can make the best choices
- simplified, timely and equitable access to a full range of support services 24 hours/day, 7 days/week
- clients and caregivers to determine the rhythm of care (especially in the home);
- shift from service needs to client needs
- need for control and choice: client-directed care
- service providers coming into the home should be knowledgeable, flexible, well-informed, caring and keep matters confidential

SUMMARY OF CONSUMER VIEWS ON HOW WE DELIVER SERVICE IDENTIFIED IN EXISTING COMMUNITY REPORTS, cont'd

- multi-cultural, multi-linguistic service providers and service providers who are trained to care for multiple types of clients
- assessing ability to pay should be done in a non-intrusive way
- assessment should include social, recreational and health needs; reassessments should occur periodically or as needed
- better appeal process for clients caregivers who are not satisfied with services or who are not getting the services they require
- provision of culturally sensitive care in a welcoming environment

SUMMARY OF AGENCY SURVEY RESPONSES TO IDENTIFYING CURRENT SERVICE CHALLENGES AND ISSUES RELATED TO HOW WE DELIVER SERVICES

- We are seeing an increasing number of elderly males with health-related concerns at our hostel for men. These men require assistance with accessing medical services and need the reassurance checks offered by the hostel staff.
- Continued attention to the social, recreation and wellness needs of people with physical disabilities
- Specialized target groups require research and planning to address their short and long-term needs, specifically individuals who are physically disabled and: have degenerative conditions, have aboriginal origins and those in the transitional age group.
- Cultural and Religious Needs – Cultural and religious needs for a broader choice of foods lead to increased costs for which the agency does not receive funding.
- Prevention and Wellness – There are many people in the community whose wellness depends on the provision of a wide range of community support services such as Meals on Wheels, Congregate Dining, Volunteer Visiting and Shopping by Bus. Within these services, flexibility and choice (e.g. Meals for ethnic groups) are essential. VON needs to recruit at least 500 new volunteers annually to maintain the existing service with the compliment of 1600 volunteers. Most people will never need to access "home care" or institutional care if they have these choices in the community.
- Language Issues – It is difficult to find volunteers with the necessary language skills and cultural background to visit those with specific language/cultural needs.
- Many consumers report living in conditions of poverty, often inadequately housed and relying on essential community supports (e.g. food banks) for survival. In addition, poverty often prevents adequate integration within the community. This is particularly true when considering the shortage of attendant outreach or affordable, supportive housing.

APPENDIX B

LIST OF INDIVIDUALS INVITED TO THE COMMUNITY CONSULTATIONS

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Sandra Barbadoro, Hamilton Family Network
Nancy Beguine, Catholic Family Services
Norma Berti, Regional Senior's Advisory Committee
Carmen Bian, Regional Seniors Advisory Committee
Gertrude Cetinski, Alzheimer Society for Halton-Wentworth
Lynn Corbey, Community Rehab Associates
Melanie Corning, Tele-Touch
Jean Lillie, CCAC
Lynne Edwards, Senior's Activitation Maintenance
Heather Elbard, Chedoke Child & Family Centre
Beth Ellis, Dr. Bob Kemp Hospice Foundation
Judith Evans, Wentworth Lodge
Family Caregiver Connection
Bill Fuller
Jane Grech, Brain Injury Services of Hamilton
Karen Hadden, Ancaster Information Services
Susan Hall, VHA Health & Home Support
Barbara Italiano, Hamilton Family Network
Marilyn Irish, Red Cross, Flamborough
Morteza Jafarpour, Settlement & Integration Services
Shallah Jamal, Hamilton Health Sciences Corp.
David Jewell, Regional Discharge Planning Committee
Robert Kendrick, Canadian Hearing Society
Sandra Knoll, Regional Advisory Committee for the Physically Disabled
Const. Liz Latmer, Community Services, Elder Abuse
Dr. Ken LeClair
Steve Mahler
Bill Mahoney, Chedoke Child & Family Centre
Dale Marshall, VON Day Centre
Shelley Marshall, Family Mental Health Network
Mickey McCallum
Heather McGavin, Chedoke Child & Family Centre
Mike Meyer, Catholic Family Services
Pat Morden, Shalom Village
Harry Nigh, Welcome Inn
Janis North, VON
Paul O'Krafka, St. Joseph's Villa
Oksana Plawniuk-Fisher, Contact Hamilton-Wentworth
Mae Radford, VON
Laura Ramsay
Brad Raspberry, St. Elizabeth Visiting Nurses' Assoc.
Gayle Rivers, Participation House
Rev. Wendy Roy, St. Matthew's House
John Ruetz, St. Peter's Hospital

Joan Savoie, Red Cross, Flamborough
Ann Scott, LTC Regional Office
Pat Scott, Glanbrook Home Support
Mary Sinclair, Regional Senior's Advisory Committee
Paula Trudell, Red Cross, Flamborough
Dr. Bruno Vedelago
Mary Walford, The Vertabraves
Lisa Weintraub, Centre de sante communautaire
Laura Williams, De dwa de dehs ny>s
Barb Worth, Complex Continuing Care Centre, Hamilton Health Sciences Corporation
Judith Zsoldos, Catholic Family Services

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